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Communiqué
Public Health Research, Education and Development Program

Sudbury & District Health Unit
Service de santé publique

THE NORTHERN ONTARIO PERINATAL AND CHILD HEALTH SURVEY: PARTNERSHIPS AND PROCESS

Introduction

The **Northern Ontario Perinatal and Child Health Survey** gathered new data on perinatal and child health through a 2002 telephone survey of 3,456 northern Ontario mothers with children six years of age and younger. The results of this survey offer much-needed information for perinatal and child-focused program and service planning throughout Northern Ontario and at the individual health unit level. Health units and community partners will use the data to improve intervention strategies and policies targeting families with children aged 0-6. The focus of this article is to describe the process and the collaboration of Northern partners that made this possible. A follow-up article will focus on the findings and implications of the survey.

In September 2000, the Ministry of Health and Long-Term Care, Public Health Branch, received funding from the Government of Ontario to support health unit-based Early Years projects. In 2002, as part of the overall Ontario Early Years initiative, each health unit was eligible for funding for Perinatal and Child Health Survey Strategies. The four key action areas identified as priorities for funding in the First Ministers' Meeting Communiqué on Early Child Development[1] were:

- Promoting healthy pregnancy, birth and infancy
- Improving parenting and family supports
- Strengthening early childhood development, learning and care
- Strengthening community supports

After discussion among health units and partners across northern Ontario, a decision was made to pool some of these resources to maximize the use of the funds and the scope of the projects. As a result, the Northern Ontario Perinatal and Child Health Survey Consortium was established. The Consortium has representation from the eight northern health units: Algoma, Muskoka-Parry Sound, North Bay & District, Northwestern, Porcupine, Sudbury & District, Thunder Bay District, and Timiskaming, as well as the Northern Health Information Partnership (NHIP), and the three Northern universities: Lakehead, Laurentian and Nipissing. The Consortium is coordinated by the Public Health Research, Education & Development (PHRED) Program at the Sudbury & District Health Unit.

The Consortium undertook three interconnected initiatives. One key project was the **Northern Ontario Perinatal and Child Health Survey (NOPCHS)**. The survey was conducted between March and June 2002. The survey is closely linked to a companion report also undertaken by the Consortium – the **Northern Ontario Baseline Child Health Information: Analysis of Secondary Data.** The "Baseline Report" presents existing data from secondary sources on the health of Northern Ontario children aged 0-6, and provides a very useful compendium of information to supplement the survey findings.

Development of the Partnership

In January 2002, a teleconference was organized jointly by the Public Health Research, Education & Development (PHRED) Program at the Sudbury & District Health Unit and NHIP to discuss the announcement of this initiative. Representatives from the eight northern health units and Lakehead and Laurentian Universities joined NHIP and PHRED for this initial discussion. The purpose of the teleconference was to share ideas and discuss the best approach to move forward on the development of perinatal and child health survey strategies. Teleconference participants discussed the benefits that could be gained by collaborating on specific elements of the initiative, especially sharing data collection, processing and dissemination strategies.

The group decided that pooling some of the allocated funds and developing a joint project could provide a unique opportunity to address the development of perinatal and child health survey strategies in a way that far exceeded the work that could be accomplished by any single health unit. As a result of this decision to work together, a consortium of research and program staff emerged.

The project had two key objectives: quality data to guide northern child health program and policy decisions, and a strong collaboration between northern health units, all three northern universities (Nipissing University joined the partnership at a later stage, thereby creating a consortium that included all northern universities), NHIP and the Sudbury PHRED Program. An important benefit of this partnership was the link between research and program expertise. The survey results obtained would be comparable across northern Ontario, and the cooperative effort would result in a more comprehensive report with increased scientific rigour and program relevance. In addition to the data that would be produced, it was felt that the project also provided a unique opportunity for northern health units and community partners to strengthen existing northern partnerships through further collaboration. Pooling resources also provided support to some health units that had less access to research and epidemiological resources.

Consortium members agreed that the Sudbury PHRED would act as the coordinating site for the project, and PHRED was given responsibility for organizing teleconferences, facilitating close collaboration, coordinating the shared budget, and ensuring that reporting requirements were met.

Letters from each northern health unit confirming their participation in the joint northern initiative were forwarded to the Ministry of Health and Long-Term Care. The support of the medical officers of health and program managers was a key success factor. For Ministry reporting, project contacts were identified for each northern health unit. The health unit representatives also acted as key information links to their organizations and communities, by gathering input on information needs, key indicators, and dissemination strategies. In particular, health unit contacts solicited feedback on pertinent topics and potential survey questions from their health unit staff and from community partners such as Ontario Early Years Centres.

Partnership Challenges and Recommendations

As with any innovative approach, there are some lessons to be learned. One key lesson for our group from the 2002 experience is that a **designated project coordinator position** is necessary for an initiative of this magnitude. There were twelve partners across the North, and changes in representation due to staff turnover added to the complex communication. To overcome the challenges of geographic distance and multiple demands on partners' time, a consistent contact person with time dedicated to the project is required. In 2002, the coordination was an in-kind contribution of the PHRED program. The time demands proved such that for 2003, the Consortium agreed to use some of the pooled funds to hire a part-time project manager and a part-time project assistant.

Our experience with this northern Ontario initiative suggests several other lessons learned and recommendations for similar projects. Frequent contact among all group members is essential to contribute to the ability to work together and stay informed. Teleconferences were held at least monthly and one face-to-face meeting was held. Although e-mail was extremely useful for sharing information, it is not as successful when seeking input or for shared decision-making. The sense of ownership of the project is enhanced when there is **frequent regular contact** and various modes of communication are used.

An important ingredient that made this initiative possible in Northern Ontario is our history of working together. Due to limited resources and the challenges of geographic distance and generally poorer health indicators, northern organizations have learned to work together to do 'more with less'. The ability to **build on existing partnerships** is essential to make these projects possible, especially when facing extremely short timelines as with this initiative.

In partnerships between practice and research centres, **sensitivity to the different types of contribution** as well as varying levels of capacity is an important consideration. For smaller health units with limited epidemiological and research support, there may be limitations on the extent of their participation in the research aspects of the project. However, the value of program expertise to keep the research grounded and pertinent was recognized as critical to the success of the project. There was appreciation of the work that everyone contributed, from the program, research and community partner perspectives.

With respect to process, **agreement on the overall goals** of the initiative is paramount. This common vision offers a framework for putting individual preferences aside in order to reach those goals. Initial time spent agreeing on the process to be followed helps to ensure a successful outcome agreeable to all. For example, if a smaller group is charged with making final cuts to the questionnaire, the entire group needs to know how they can provide feedback, who will make the final decisions, and on what basis those decisions will be made. The assignment of key tasks

must be decided with group input and agreement. Furthermore, accountability for key tasks is necessary. In order for the consortium to have an acceptable level of comfort, contracts for significant parts of the work need to be developed that clearly outline the process and deliverables expected. The contracted work is then carried out with the understanding that the consortium will receive the desired product with the level of quality and within the time period expected. This was critical when the timelines for this project were so short – a one-year period to develop the partnership, develop the tools, collect and analyze the data and produce a report.

The partnership has paid dividends in terms of the quality and breadth of the work produced to date. As evidence of the satisfaction with the partnership, Consortium members agreed in 2003 to pool funds once again to continue the work begun in 2002. Furthermore, the links among northern health units and partners have been strengthened and our association will continue beyond the bounds of this project.

Development of the Survey

Topics were proposed based on needs of program staff and community partners for current data to guide program and policy decisions. The selected main topic areas were:

- Parenting
- Breastfeeding
- Unintentional Injuries and Safety
- Asthma
- Food Security
- Prenatal and Child Nutrition

Literature searches and consultation with health unit staff, partner agencies, Health Canada, Statistics Canada and others yielded possible questions to include. Whenever possible, questions for the survey were drawn from existing tools that have a demonstrated level of reliability and are valid for use in community samples, e.g., National Longitudinal Survey of Children and Youth, and the National Population Health Survey – Child Health Module.

The initial questionnaire was quite lengthy – pre-testing showed an average duration of 37 minutes. Based on cost and participant considerations, 25 minutes was determined to be the maximum acceptable length. Therefore, the consortium reduced the number of questions to a time-manageable set while maintaining the construct validity of the survey tool. Consortium members and area content experts from health unit program staff identified potential cuts, and when three or more selected an item or section for deletion, it was considered a candidate for deletion. Principal components analysis results from early pre-testing were also used to identify possibly redundant items. Care was also taken to ensure that the remaining questions would provide enough depth, breadth and quality to be useful. The ultimate goal of providing policy- and program-relevant data was the overall guiding principle.

Three telephone data collection agencies were contacted in order to obtain quotes for conducting 650 phone interviews of mothers of children 0-6 years of age per health unit across eight northern health units (total sample of 5200). Based on both their capabilities and offered price, Oraclepoll Research Limited was selected to conduct the telephone surveys.

Individuals from the health units were provided with an opportunity to monitor the initial pilot testing of telephone surveys and provide feedback on question revisions. The questionnaire was translated into French by an accredited translator. The final version of the survey was pilot tested in both French and English, and after minor revisions for clarity, the final questionnaire was submitted to the Sudbury & District Health Unit Research and Ethics Committee for ethical review.

Sample

The telephone survey targeted northern Ontario mothers of children aged 0-6. Only mothers were contacted for the survey, since several topic areas, such as breastfeeding and folic acid intake during pregnancy, were only applicable to mothers. For mothers with more than one child aged 0-6, the survey focused on the child who had the most recent birthday (the 'target child') in the family. This 'target child' approach ensured an equal chance of selection among the eligible children in a family.

The initial sample size for each health unit was determined using the formula of Pagano and Gauvreau,[2] with prevalence of 50%, 80% power (β=.20) and α=.05. This gave sample sizes in the range of 550 to 650 per health unit from smallest to largest health unit. The population on which the sample was determined was the number of households with children aged 0-6. To estimate the number of households with children aged 0-6, 8% of total population in each health unit area was used. The population for each health unit was calculated based on information from the

1996 Census. Population numbers in the north have generally decreased between the 1996 and 2001 censuses. The original sample size was generous, allowing for sub-group analysis. Due to the length of the survey, resource constraints and difficulty in recruiting mothers with children aged 0-6 through random digit dialing, the sample size was reduced, while still maintaining sufficient numbers per health unit area to ensure reliable estimates for the primary questions of interest. Due to the reduction in sample size, some sub-group analyses may not be possible.

Each health unit agreed to provide 300 names from their respective catchment areas of mothers from the Integrated Services for Children Information System (ISCIS) database who had consented to participate in the study, with the remaining 350 to be contacted by random digit dialling. Due to unanticipated difficulties in reaching the desired number of completed surveys, the numbers were reduced to between 400 and 456 for each of the eight health unit areas, for a final overall sample size of 3,456. Those health units that were able to recruit more mothers through the ISCIS database received a larger final sample size.

The sample was, therefore, drawn from two sampling frames: the ISCIS database and random digit dialing. Overall, 56% of the sample was from ISCIS and 44% from random digit dialing (RDD).

ISCIS

The ISCIS database contains the names and contact information for mothers of newborn children who are residents of each health unit's catchment area. Because health units are required to contact all mothers who have given birth in their catchment area within 48 hours after the child's birth, the ISCIS database covers the universe of Ontario mothers who have given birth since July 1999.

In order to recruit mothers from the ISCIS database, a recruiting procedure and an extraction protocol were developed. The Sudbury PHRED developed a consent script, which was approved through an ethics review process, as well as a package to train the lay home visitors who were to carry out the subject recruiting. Contact was made with each mother by the trained recruiters from each health unit, who asked for her consent to be contacted by the surveyors. A one-page summary information sheet that could be mailed out to individuals requiring additional information was also developed. All the material was made available in both English and French. Names were extracted randomly from the ISCIS database for births between September 2000 and August 2001. Starting from the last day of the month, 50 mothers' names were extracted for each month. Names were excluded if the child was known to be deceased or if the mother was known not to speak English nor French. (In the 1996 census, 3.2% of Northern residents spoke neither English nor French.) Contacts were made until 25 consents per birth month, for a total of 300 names, were obtained, although the number per month was topped up from other months if one month did not yield 25 consents. The consented names and telephone numbers were then provided to the survey firm.

The above-described process of obtaining names from ISCIS ensured a random selection of mothers from the ISCIS database. One of the limitations of using the ISCIS database as described was that it selects mothers who have given birth recently, and thus, the sample was skewed towards mothers with younger children. However, the target child may be a child other than the one in ISCIS database, if a mother has more than one child under the age of 7.

Although it had been anticipated that the ISCIS numbers would provide a very high rate of completed interviews, because the mothers had already agreed to be contacted for the survey, approximately 20% of the ISCIS contacts declined to participate when contacted by the surveyors. Because of the time taken to reduce the length of the survey, we were not able to contact the mothers as quickly as we had indicated initially, and, therefore, the mothers may have forgotten about the initial contact or may have changed their minds in the interim. It is also possible that a social desirability bias was operating when the mothers agreed to have their names go forward to the survey firm, but then they declined when approached by an unknown caller from the survey firm.

Random Digit Dialing (RDD)

All mothers with a listed phone number have an equal probability of being selected from the RDD sample. Limitations include exclusion of mothers that do not have a phone, those living in institutions, and unlisted phone numbers. According to information from the survey firm, only a small percentage of individuals in Northern Ontario have unlisted phone numbers. In order to avoid duplicate contacts, the RDD contacts excluded the numbers provided through the ISCIS database.

Data Collection Process

Data collection began at the end of March 2002 and was completed by the end of June. Phone calls were made

during various times throughout the day including evenings and weekends. Mothers who were busy or not available at the time of the initial phone call could set up a time for a later date. For all calls, surveyors asked to speak with the mother of a child 6 years of age or under who lives with her. If there was no answer, the surveyors made up to 15 repeat calls to each number.

Weighting

The weight assigned to respondents was based on two factors. First, a weight was calculated so that the distribution of children's ages 0-6 matched the population distribution within each health unit area, correcting for over-representation of younger children in our sample. The second level of weighting was for health unit population, in order to account for proportional under-representation of mothers in larger health unit areas in the calculation of northern rates (see Figure 1).

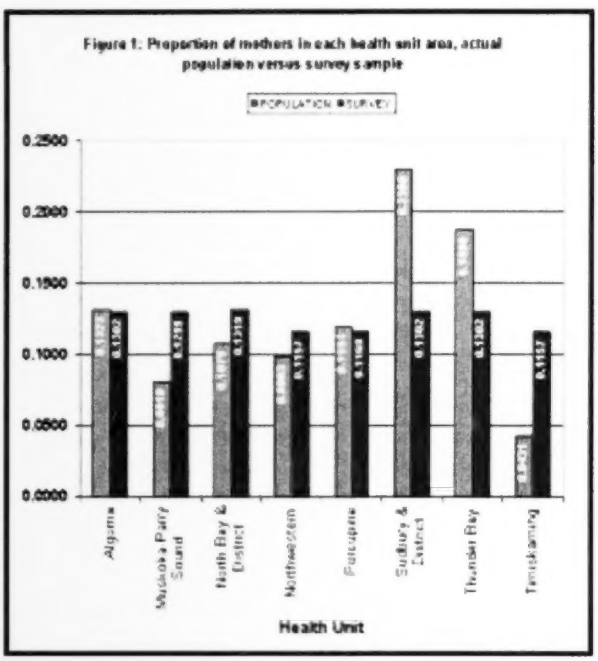

Figure 1: Proportion of mothers in each health unit area, actual population versus survey sample

The differences in proportion are explained by the fact that a similar number of people were sampled from each health unit. Therefore, a weight was calculated to adjust the proportion of mothers to be representative of the distribution of mothers by health unit area. The final weight is a product of the two weights. Generation of weights were based on age distribution data and the 2001 population estimates from the NHIP population data cube (age 0-6), from the Provincial Health Planning Database, Ministry of Health and Long-Term Care.

Conclusion

This article provides an overview of the partnership and the process required to make this initiative possible. From the outset, there were two main objectives to the NOPCHS initiative. First, we sought to obtain high quality data to guide northern child health program and policy decisions, especially in the area of health promotion. The Highlights and Baseline Reports have been welcomed by health unit program staff and by community agencies that serve children and families. Second, we hoped to achieve a strong collaboration between northern health units, northern universities, NHIP and the PHRED Program. The Northern Ontario Perinatal and Child Health Survey Consortium has developed a highly successful and productive partnership. The work of the Consortium continues in 2003, with additional funding from the Ministry of Health and Long-Term Care. Five focused reports on topics covered in the survey are being produced and will be available by the end of 2003.

A follow-up article will outline the key findings and program, policy and service implications of the survey for the promotion of the health of northern Ontario children.

French language versions of the reports will be available shortly. The Highlights and Baseline Reports, and Executive Summaries in French, are available online at:

http://www.sdhu.com/english/statistics/htmlfiles/Statistics_Health_Status_profiles.html.

ACKNOWLEDGEMENTS

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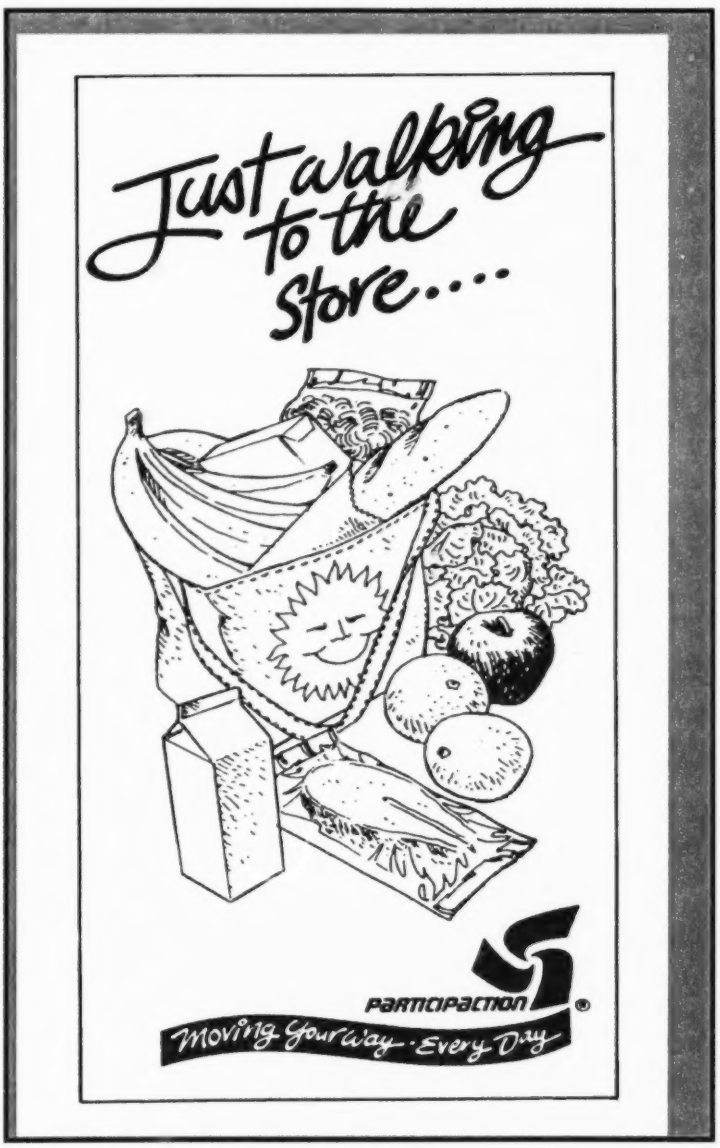

Summary of Reportable Diseases in Ontario - March, 2003

Health Units by Region	Population 2000	AIDS	Campylo.	Chicken-pox	Chlamydia	Enceph./ Meningitis	GAS	Gonorrhea
Algoma	125,109				20			3
North Bay	93,505		1	34	10		2	
Northwestern	91,920			4	19		2	
Porcupine	93,680			3	11			1
Sudbury	199,619			63	25	1		
Thunder Bay	158,698		1		34			3
Timiskaming	37,721		1		6			
Total - Northern	**800,252**		**3**	**104**	**125**	**1**	**4**	**7**
Eastern Ontario	194,945			3	19			
Hastings & Prince Edward	159,088		4		15			
Kingston, Frontenac & Lennox	180,225				35	1		2
Leeds, Grenville & Lanark	163,143		2	4			1	
Ottawa	779,274		21	101	83	2	4	7
Renfrew	101,131		3		7		1	
Total- Eastern	**1,577,806**		**30**	**108**	**159**	**3**	**6**	**9**
Durham	512,271		12	364	45	3	4	5
Haliburton-Kawartha	168,120		1		14			
Muskoka-Parry Sound	86,218			6	4			
Peel	1,008,163		26	204	135	3	2	19
Peterborough	128,881		2	17	20	1	1	
Simcoe	377,405							
Toronto - total	2,542,844	2	54	313	457	9	6	146
North	*627,021*		*14*	*85*	*82*		*1*	*21*
South	*688,584*	*2*	*22*	*39*	*174*	*2*	*2*	*82*
East	*717,937*		*11*	*47*	*131*	*4*	*2*	*24*
West	*509,302*		*7*	*142*	*70*	*3*	*1*	*19*
York	724,969		27	48	43	1	1	9
Total - Central East	**5,548,871**	**2**	**122**	**952**	**718**	**17**	**14**	**179**
Grey Bruce	157,664		1	20	14			
Elgin-St. Thomas	84,182		4	13	6		1	
Huron	61,097		1					
Chatham-Kent	112,897			5	7			
Lambton	131,643							
Middlesex-London	412,976	1	6		29	2		4
Oxford	102,561		1		11			
Perth	75,238		1	7	4	1		
Windsor-Essex	381,672		15	92	35		1	4
Total - Southwest	**1,519,930**	**1**	**29**	**137**	**106**	**3**	**2**	**8**
Brant	126,481			71	13		1	
Haldimand-Norfolk	109,536		2		6		1	
Halton	375,705		9		10	1	2	1
Hamilton	498,553		5	29	91	1	2	11
Niagara	423,600		10	127	50	1		3
Waterloo	446,833		9		68	2	1	7
Wellington-Dufferin-Guelph	241,777		4	40	17			
Total - Central West	**2,222,485**		**39**	**267**	**255**	**5**	**7**	**22**
March 2003	**11,669,344**	**3**	**223**	**1,568**	**1,363**	**29**	**33**	**225**
*** Total YTD 2003**	-	**19**	**660**	**4,075**	**4,462**	**76**	**136**	**709**
*** Total YTD 2002**	-	**29**	**716**	**4,573**	**4,529**	**86**	**129**	**772**

The Toronto City regions above are now defined as: North - former North York; South - former City of Toronto; West - former Etobicoke and City of York; East - former Scarborough and East York

**Infectious Syphilis cases include 'Primary, Secondary and Early Latent' staging effective January 1, 2003

*** Adjusted for deletions and late reports.**

Summary of Reportable Diseases in Ontario - March, 2003

Health Units by Region	Population 2000	Hepatitis A	Hepatitis B	Hepatitis C	Hib	Influenza	Measles	Meningococcal
Algoma	125,109			4				
North Bay	93,505			5		3		1
Northwestern	91,920			2				
Porcupine	93,680							
Sudbury	199,619			6				
Thunder Bay	158,698			9		5		
Timiskaming	37,721							
Total - Northern	**800,252**			**26**		**8**		**1**
Eastern Ontario	194,945			4		2		
Hastings & Prince Edward	159,088		1	2		1		
Kingston, Frontenac & Lennox	180,225					1		
Leeds, Grenville & Lanark	163,143			1				
Ottawa	779,274			40		3		
Renfrew	101,131			1		1		
Total- Eastern	**1,577,806**		**1**	**48**		**8**		
Durham	512,271					1		
Haliburton-Kawartha	168,120		1	7		1		
Muskoka-Parry Sound	86,218	1		1		1		
Peel	1,008,163	2		24		12		1
Peterborough	128,881			14				
Simcoe	377,405							
Toronto - total	2,542,844	2		120		16	2	
North	*627,021*	*2*		*18*		*3*	*1*	
South	*688,534*			*52*		*8*		
East	*717,937*			*32*		*4*	*1*	
West	*509,302*			*18*		*1*		
York	724,969	1	1	11		4		
Total - Central East	**5,548,871**	**6**	**2**	**177**		**35**	**2**	**1**
Grey Bruce	157,664			6		8		
Elgin-St. Thomas	84,182			4				1
Huron	61,097							
Chatham-Kent	112,897					4		
Lambton	131,643							
Middlesex-London	412,976			13		4		1
Oxford	102,561			1				
Perth	75,238			1				
Windsor-Essex	381,672			12				
Total - Southwest	**1,519,930**			**37**		**16**		**2**
Brant	126,481			5				
Haldimand-Norfolk	109,536			1				
Halton	375,705			8		3		
Hamilton	498,553	1		35				
Niagara	423,600			26		2		
Waterloo	446,833			11				1
Wellington-Dufferin-Guelph	241,777			2				
Total - Central West	**2,222,485**	**1**		**88**		**5**		**1**
March 2003	**11,669,344**	**7**	**3**	**376**		**72**	**2**	**5**
*** Total YTD 2003**	-	**23**	**18**	**1,220**	**1**	**327**	**4**	**14**
*** Total YTD 2002**	-	**32**	**33**	**1,323**		**1,928**		**13**

The Toronto City regions above are now defined as: North - former North York; South - former City of Toronto; West - former Etobicoke and City of York; East - former Scarborough and East York

**Infectious Syphilis cases include 'Primary, Secondary and Early Latent' staging effective January 1, 2003

* Adjusted for deletions and late reports.

Summary of Reportable Diseases in Ontario - March, 2003

Health Units by Region	Population 2000	Mumps	Pertussis	Rubella	Salmon.	Shigellosis	Syphilis Infectious**	VTEC
Algoma	125,109	3						
North Bay	93,505				1			
Northwestern	91,920							
Porcupine	93,680		1					
Sudbury	199,619				1	1		
Thunder Bay	158,698				2			
Timiskaming	37,721							
Total - Northern	**800,252**	**3**	**1**		**4**	**1**		
Eastern Ontario	194,945		1		3			
Hastings & Prince Edward	159,088		1		4			1
Kingston, Frontenac & Lennox	180,225							
Leeds, Grenville & Lanark	163,143				1	1		
Ottawa	779,274				10	6	2	1
Renfrew	101,131				1			
Total- Eastern	**1,577,806**		**2**		**19**	**7**	**2**	**2**
Durham	512,271				5			1
Haliburton-Kawartha	168,120				2			
Muskoka-Parry Sound	86,218							
Peel	1,008,163		1		12	1		1
Peterborough	128,881		4					
Simcoe	377,405							
Toronto - total	2,542,844		1	1	36	12	17	2
North	*627,021*		*1*		*12*	*1*		
South	*688,584*				*11*	*8*	*16*	
East	*717,937*			*1*	*7*	*2*	*1*	*2*
West	*509,302*				*6*	*1*		
York	724,969		1		11	1		5
Total - Central East	**5,548,871**		**7**	**1**	**66**	**14**	**17**	**9**
Grey Bruce	157,664							
Elgin-St. Thomas	84,182							
Huron	61,097				1			
Chatham-Kent	112,897				1			
Lambton	131,643							
Middlesex-London	412,976				4			1
Oxford	102,561				1			
Perth	75,238		1		3			1
Windsor-Essex	381,672				15			
Total - Southwest	**1,519,930**		**1**		**25**			**2**
Brant	126,481				3	1		
Haldimand-Norfolk	109,536				1			1
Halton	375,705				8	2		1
Hamilton	498,553				6			1
Niagara	423,600		2		13			
Waterloo	446,833		1		5	2	1	
Wellington-Dufferin-Guelph	241,777				3		1	3
Total - Central West	**2,222,485**		**3**		**39**	**5**	**2**	**6**
March 2003	**11,669,344**	**3**	**14**	**1**	**153**	**27**	**21**	**19**
*** Total YTD 2003**		**5**	**51**	**3**	**415**	**74**	**70**	**108**
*** Total YTD 2002**		**5**	**101**	**1**	**511**	**60**	**22**	**25**

The Toronto City regions above are now defined as: North - former North York; South - former City of Toronto; West - former Etobicoke and City of York; East - former Scarborough and East York

**Infectious Syphilis cases include 'Primary, Secondary and Early Latent' staging effective January 1, 2003

* Adjusted for deletions and late reports.